DOCUMENT RESUME

ED 320 376 EC 231 190

AUTHOR Riordan, Judy; Vasa, Stanley F.
TITLE Involvement of Persons with Disabilities in Religious Practice: An Issue for Special Education.
PUB DATE 24 Apr 90
NOTE 11p.; Paper presented at the Annual Convention of the Council for Exceptional Children (68th, Toronto, Canada, April 23-27, 1990).
PUB TYPE Speeches/Conference Papers (150) -- Information Analyses (070) -- Reports - Research/Technical (143)

EDRS PRICE MF01/PC01 Plus Postage.
DESCRIPTORS *Accessibility (for Disabled); Adults; Assistive Devices (for Disabled); *Church Programs; Clergy; Counseling Services; Delivery Systems; *Disabilities; Elementary Secondary Education; Mental Retardation; Parent Counseling; *Religion; *Religious Education; Social Support Groups

ABSTRACT

The paper reviews literature related to the active participation of individuals with disabilities in religious organizations. A summary is then presented of a study conducted in a mid-sized metropolitan city of clergy perceptions of services available to individuals with disabilities and their families. The study, involving 125 clergy, examined four issues: (1) provisions available for persons with disabilities, (2) religious instruction available or modified for persons with mental retardation, (3) provisions for persons with disabilities to meet rites of passage, and (4) pastoral counseling services available to parents of individuals with disabilities. Physical accommodations for individuals with disabilities were available in a relatively low percentage of religious organizations, and included: designated handicapped parking; ramps; handrails; elevators; interpretation of worship services for individuals with hearing impairments; and braille, large print, and taped reading materials. Fifty-six percent of respondents reported that religious education was available to members with mental retardation. Fifty-eight percent indicated that modifications to preparatory instruction for rites of passage were available to persons with mental retardation. The availability of a support group for parents of disabled children was reported in 6% of responses, while 72% indicated that pastoral counseling was available to parents. Includes 23 references. (JDD)

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Involvement of Persons with Disabilities in Religious Practice:

An Issue for Special Education

A Paper Presented at

International Council for Exceptional Children Conference

Toronto, Canada

by

Judy Riordan and Stanley F. Vasa

Department of Special Education

University of Nebraska-Lincoln

April 24, 1990

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Involvement of Persons with Disabilities in Religious Practice:
An Issue for Special Education

This paper is divided into two sections: 1) a review of the relevant literature related to the active participation of individuals with disabilities in religious organizations and 2) a summary of a study conducted in a mid-sized metropolitan city of clergy perceptions of services available to individuals with disabilities and their families.

REVIEW OF THE LITERATURE

In recent years normalization of the experiences of persons with disabilities has been a major focus of special education. That principle has been as much a goal for persons with mental retardation as for those who have physical or sensory impairments. Moreover, it is a life-span issue; normalization is as critical to the quality of life for adults as it is for children. Religious organizations can provide an important aspect of normalization (Park, 1975), with involvement and influence restricted not only to childhood and adolescence as is the limitation with special education, but extending throughout adulthood.

Another dimension of the relationship of religious organizations to mental retardation involves the ethical, philosophical, and, indeed, theological issues confronting persons with disabilities, their families, and the professionals who work with them (Gaventa, 1986). The conceptualization and articulation of values relating to disabilities perhaps for many people emanate from and correspond to basic tenets of religious belief. Hoffman (1969) observed that religious organizations are "vehicles for comprehensive, unified, and delimited value groupings."

Religion is as important in the lives of persons with mental retardation as in those of people with no disabilities; expression of shared values, a source of comfort, and a place of belonging and acceptance (McAfee, 1988) are functions of religion that benefit all congregants regardless of levels of ability. However, an issue of disability that may be problematic for religious organizations is the extent of understanding necessary for practice

of and participation in faith. The equation of faith with intellectual comprehension can deny to persons with mental retardation full inclusion and participation in congregations. Yet, Gaventa (1986), who noted the exclusionary effects of assumptions that link wisdom with complexity and insight with abstraction, listed the same significance of religion for persons with disabilities as for those without: worship, tradition, fellowship, service to others, and pilgrimage.

An early study of the adult lives of persons who as children had been identified as mentally retarded (Baller, 1936) found that although more than 50 percent of the group were members of religious organizations, regular attendance at services and participation in activities were low. A more recent investigation (Schalock, Harper, & Carver, 1981) of the adjustment of adults with mental retardation who had been placed into independent housing five years prior to the study found the most frequently accessed community facilities in descending order were: church, bowling alley, restaurant, laundromat, and grocery store. A survey of recreational and leisure opportunities offered by community residential alternatives in Illinois (Wilhite, Reilly, & Teaff, 1989) indicated that only 17% of the residential programs listed religious activities as an available option. Another study, which investigated the community integration of young adults with mental retardation in Virginia, (Kregel, Wehman, Seyfarth, & Marshall, 1986) found that whereas 46% of the respondents reported attending church, only 14% reported participation in church activities such as choir or clubs. An examination of quality of life two years after high school graduation (Scuccimarra & Speece, 1990) found that young persons with mild disabilities cited television viewing (100%), movie attendance (90.6%), and church attendance (63.1%) as the social activities in which they most frequently participated. These studies indicate the important role of religious organizations in meeting the needs of disabled individuals, while also underscoring the inactive participation of persons with disabilities in religious organizations.

Disability affects not only the individual, but the entire family. The resultant necessary adjustments and adaptations, often difficult and ongoing, can strain families'

resources. Included among the major supports helpful to many families is religion, which may be to some people a more familiar, accessible, and natural source of help. Heifetz and Franklin (1982) observed that "unlike specialists, clergy are a regular, normative part of many families' lives with a routine closeness and understanding that qualify them as general practitioners and trusted referral agents." Gaventa (1986) concurred that many parents may have greater trust in their religious organization than in other private or public services that may be more readily affected by funding changes.

Support from religious organizations has been differentiated from support from religious beliefs. In a study of mothers of young children with Down syndrome, Fewell (1986) found that only 29% indicated receiving support from organized religions, whereas 66% reported deriving support from their personal religious beliefs. She noted the support parents seek from religious bodies is both educational, with opportunities for the child's participation and guidance for themselves in meeting responsibilities to the child, as well as structural, with definition and observance of major lifetime milestones. Despite the potential wealth of support that might be sought from religious organizations, many parents feel alienated (Ellis, Ellis, & Warren, 1984), resulting in greater perceived loss and isolation.

Although there are only sparse data regarding clergy's activities with persons who are mentally retarded, there is some research examining the involvement of clergy with them and their families. Heifetz and Franklin (1982) studied those activities in which pastors were involved, their perceived competence in and willingness to undertake activities, and their perceptions of the division of responsibility for such activities among clergy, parents, and secular service professionals. Results indicated both clerical perception of competence and areas of activity dealt with areas requiring little or no specialized training, only minor modifications, and short-term commitment. However, clergy felt great responsibility for but little competence in the religious training of persons with mental retardation. Peterson (1970) found that clergy's personal knowledge or contact was associated with more positive attitudes toward people with intellectual impairments, as was having had pastoral counseling

training or counseling experience. Many clergy and their congregations, however, are not prepared for involving congregants with severe disabilities (Ellis, Ellis, & Warren, 1984), and Wolfensberger and Kurtz (1969) observed that often even religious parents of persons with retardation have little guidance or comfort from their clergy.

Since few empirical data are available about the pastoral counseling role and services of religious organizations to individuals with disabilities and their families, a study was designed to examine major issues in the participation of individuals with mental retardation and other disabilities in religious organizations.

A STUDY OF SERVICE AVAILABILITY FROM RELIGIOUS ORGANIZATIONS FOR INDIVIDUALS WITH DISABILITIES

The four issues studied were: 1) provisions available for persons with disabilities, 2) religious instruction available or modified for persons with mental retardation, 3) provisions for persons with disabilities to meet rites of passage, and 4) pastoral counseling services available to parents of individuals with disabilities.

Subjects.

Participants were clergy from a Midwestern metropolitan area with about 200,000 inhabitants. The names of potential respondents were drawn from the local telephone directory Yellow Pages Index, which provided the most comprehensive listing available, since some worship centers were not members of the Local Area Fellowship of Churches. Initially 205 surveys were distributed and 85 were returned. Three weeks later a follow-up letter and survey were sent to those who did not respond to the earlier request. A total of 125 were returned (60%).

The survey contained 13 forced response questions that addressed issues regarding disabled congregation members. Items were designed to gather information in the following areas: provisions available for persons with disabilities, religious instruction available or modified for persons with mental retardation, pastoral counseling services available to families, and provisions for persons with disabilities to meet rites of passage.

Results and Discussion

Physical Accommodations for Congregants with Disabilities

The accommodations for individuals with physical and sensory handicaps vary. Designated handicapped parking was provided by 61 percent (n=77); ramps, 47 percent (n=58); handrails, 51 percent (n=64); and elevators, 17 percent (n= 21). Some respondents indicated that their facilities were barrier free and located on one floor.

Interpretation of worship services for individuals with hearing impairments was provided by 10 percent (n=12) of the religious organizations and amplification devices were provided by 53 percent (n= 65), while accommodations for individuals with visual impairments were provided as follows: braille reading matter, 8% (n=10); large print reading matter, 51% (n= 64); and taped reading materials, 42% (n = 53). The relatively low percentage of religious organizations responding positively to the availability of accommodations for individuals with disabilities may be based on economic constraints and clergy's lack of training or awareness of possible modifications as well as their comfort level in working with these persons. In some cases, clergy may not have realized that members of their congregations have disabilities.

Religious instruction for persons with mental retardation

Fifty-six percent of the respondents reported religious education was available to members with mental retardation. Forty percent reported mentally retarded individuals were taught in regular religious education classes, while 57 percent reported access to instructional materials for the religious education of persons with cognitive impairments. Separate classes were available for persons with mental retardation as follows: children (20%, n=25), teenagers (18%, n=22), and adults (13%, n=16). Availability of religious education teachers to instruct individuals who are mentally retarded was reported by 43 percent (n=54) of the respondents, and available space for classes was reported by 52 percent (n=65). Participation of persons with mental retardation in social/service/study groups available within the congregation was reported by 50 percent (n=62) of the respondents.

Provisions for membership and meeting rites of passage

Ninety percent (n=112) of the respondents reported offering preparatory instruction to persons desiring membership, and 58 percent (n=72) indicated that modifications to that instructional process are available to persons with mental retardation. Mental retardation was perceived as a barrier to rites of passage necessary to full participation in the faith by only six percent of the responding clergy. Some comments from respondents about meeting the rites of passage included: "A Bar Mitzvah would be difficult or perhaps impossible...," "...must fully understand what is required...", "...assumption made that the person will be able to read, write and move without help." These responses suggest that although some clergy realize the limitations of mental retardation, many are unaware of the implications of the disability and modifications or accommodations necessary for active participation.

Pastoral counseling services available to parents

The availability of a support group for parents of disabled children was reported in 6 percent (n=8) of responses, whereas 72 percent (n=90) indicated that pastoral counseling was available to parents. Respondents were asked to rank order the top five issues for which parents of disabled children most frequently seek counseling or support from among the following items: (1) crisis of faith, (2) reasons for having a disabled child, (3) parents' reaction to disability, (4) family stress associated with disability, (5) dealing with siblings' reactions, (6) religious education of disabled child, (7) disabled child's participation in congregation, (8) theological issues of disability, (9) child rearing issues, (10) long-term planning for disabled child, and (11) other. [Each response was tabulated as follows: rank of 1, 1 point; rank of 2, 2 points; rank of 3, 3 points; rank of 4, 4 points; rank of 5, 5 points, no rank, 6 points]. The rank for each issue was tabulated, resulting in this composite hierarchy:

1). family stress associated with disability,

2). parents' reaction to disability,

3). reasons for having a disabled child,

4). child rearing practices, and

5). crisis of faith.

CONCLUSIONS AND RECOMMENDATIONS

There is a need for special educators to assist clergy in understanding the needs of individuals with disabilities and accommodations which would enable their more active participation in religious organizations. The low number of identified individuals with handicaps in the congregations suggests that clergy either are not aware of the population of disabled members or may not have offered opportunities for these individuals or their families to actively participate.

Clergy members may need to be made aware of the personal counseling needed by families of disabled members. The study results suggest a sizeable minority of clergy either are not comfortable counseling with parents and families of disabled members or may not recognize a need for such services. Many clergy perhaps are unaware of the chronicity of adjustments and crises confronted across the life-span by parents and families of individuals with disabilities.

Mental retardation was not viewed as a significant barrier to meeting rites of passage which might indicate incomplete awareness of the cognitive limitations of more severe mental retardation. Members with severe disabilities need more proactive accommodations to enable them to actively participate.

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